



Independent living

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Enil's Submission Of Our “Eight Key Demands” To The Mep Disability Intergroup At The European Parliament

By Enil President John Evans,

24th SEPTEMBER 2003

Introduction

Firstly on behalf of ENIL can I thank you for finding time to arrange this meeting in order that we can make our presentation. We value the opportunity very much in being able to discuss with you the very important subject of Independent Living and Personal Assistance services, and in particular the 8 Key Demands we have formulated for this occasion.

As the representative European organisation of disabled people, who need Independent Living and Personal Assistance, we felt it was important to bring these issues to the European Parliament. We are a Human Rights grass-roots organisation, who are very much in touch with the needs and wishes of disabled people, and feel that these “8 key demands” are very much current in the wishes of disabled people.

Eight Key Demands

1. A European Wide Policy On Personal Assistance

We believe that the availability of Personal Assistance Services is long over due as there are still many countries within the European Union, who still do not have established and effective personal assistance services for their disabled people. We felt this issue to be very pertinent this year as it is the European Year for Disabled People. It became one of ENIL's aims of the year to try and publicise and implement this more.

As personal assistance services are essential in enabling disabled people to live independently we felt this was following on from the calls for Independent Living in both the Madrid and the Tenerife Declarations. We feel it is important now to build upon this recognition as both of these declarations came out within fourteen months of each other and this is why we want to



bring these to the attention of the European Parliament. We also think that our “8 Key Demands” fit well in the above declarations.

2. Institutionalisation

We believe that self-determination and independent living should be a basic right for disabled people who aspire to it. The opportunities to live independently provide a sane alternative to institutionalisation, which is both healthy to the individual and economic for the State. As institutionalisation is part of the current framework of the social exclusion policies of the EU, it makes common sense for the EU to support Independent Living in community services as a viable alternative to disabled people living in institutions.

As long as Institutions exist, the spectrum of a disabled person finally ending up in one is a fear that haunts most disabled people throughout their lives. Institutional life denies a person, real citizenship and participation in the community. It also takes away ones freedom. For those disabled people who have already experienced institutional living and have tasted that reality and the loss of control over the basic decisions of their life, know only too well, that it is a large price to pay, sacrificing ones own contribution and livelihood in the community.

As I speak I shiver at the thought that right now at this moment in time there are thousands of disabled people in institutions in every EU Member State. I dread to think of what the exact numbers of disabled people are in institutions throughout Europe. It touches me deeply especially as I have personally experienced some years in an institution myself. I was one of the lucky ones who originally pioneered Independently Living in the UK as a solution, in order that we could get out and escape from the imprisonment of institutional living.

For a disabled person living in an institution these are just a few of the sacrifices that one makes in terms of losing ones basic Rights:

- Are denied their rights by having to live in institutions
- Do not have the right over decisions that affect their lives
- Are often denied choice and control over their lives
- Do not have the right over who gets them up and puts them to bed
- Do not have the right when they can get up and go to bed
- Do not have the right to chose their own personal assistance
- Do not have the right to basic services
- Do not have the right to decent housing
- Do not have the right as to when and what they can eat
- Do not have control over their own money - as many institutions withhold their pocket money and benefits which they receive from the state

This paints a bleak and gloomy picture, which makes one realise why disabled



people are fearful over the spectra of ending up in an institution. This is without even touching on the bad conditions they live under and the potential physical and sexual abuse and victimisation they experience.

3. Representation of Disabled People In European Social Inclusion Strategies

The answer to this is social, economic and political. This is because of the lack of implementing good social policy practice excludes disabled people. This is ironic especially when we live in a time when the directives from the European Union and National Governments are towards social inclusion. This is meant to include disabled people in all aspects of life, social, political and economic, yet what happens sometimes is the opposite. Disabled people find themselves victims of a system that disenfranchises them and keeps them at the poverty level, dependent on benefits, lacking opportunities in employment and training, and further isolated in their own communities because of inaccessible public transport systems.

From a social perspective much of it stems from bad social policy planning, but the root cause is through fear, ignorance and a poor attitude to including disabled people in the main stream of life. There is a lack of commitment both by the EU and national and local Governments to address this problem. This is clearly indicated in many instances where disabled people and their representative organisations are excluded from any real involvement in planning teams in developing appropriate services. There is still a problem fully understanding what real consultation and user participation is all about. They neglect it at their peril, but unfortunately it is disabled people who are the real victims in the end by not getting the services they require. There should be a continuation from beginning to end in the planning and delivery of proper, appropriate services. This should work from the top down, from national government policy and legislative level to the regional and local government levels. In this process there should be forums, networks, planning and consultation groups that constructively involve disabled people as real participants, planners and experts in their own affairs.

4. The Right to Gain Personal Assistance Services Regardless Of Impairment, Ethnicity Or Age

In order to avoid social exclusion to different impairment groups in the provision of personal assistance services it is essential that this is planned and delivered equitably right across the board. This should also include ethnicity and age.

5. Promotion of the Appropriate Implementation Of The Philosophy Of Independent Living

Independent Living has been a catalyst for the Disability Movement in the struggle for both our Civil and Human Rights. It has provided us with a framework with which we can both challenge and monitor the structures of society. Independent Living touches upon the nerve fibres of everything we do in our every



day lives. This is why it is so important in highlighting our needs and aspirations, and at the same time it significantly provides us with a direction to progress our overall movement.

Independent Living has provided us with many answers and solutions to the problems and discrimination we face. It has become our blue print for survival and liberation. Through the philosophy and practice of Independent Living, disabled people have been able to regain more control and power over their lives. We have been able to organise and develop our own organisations, and at the same time operate more control and choice over our life styles by setting up our own Independent Living, Direct Payments or Personal Assistants Schemes. It has helped to politicise many disabled people.

We encourage the EU to support the implementation of the Independent Living philosophy.

6. Overseas Development Aid for Disabled People

We feel that it is important that the European Union takes a lead in developing community projects for disabled people in developing countries. This is because disabled people in these countries experience extreme hardship and poverty and the lack of basic fundamental services due to the economic conditions of their countries.

A number of Scandinavian countries and some international disability organisations have already some very good models of practise in this field that can be built upon.

7. Disabled People's Human Rights Violations

We think that as disabled people's human rights are still being violated in many European countries it is very important that the legal instruments of antidiscrimination legislation are strengthened. The non-discrimination clause in the Amsterdam Treaty is a step in the right direction but we need much stronger enforceable legislation in order to protect the rights of disabled people in the EU.

8. The Right to Retain Personal Assistance Funding When Moving Around Eu Member States

For some time now ENIL has felt strongly about this, especially as it restricts the freedom of movement of disabled people, unlike other non-disabled citizens of Europe. We were encouraged at the recent advance at the European Parliament of the progress of the new social security regulation allowing that benefits could become exportable throughout the EU for disabled citizens.

In Conclusion

So we come to the European Parliament to meet our MEP's and yourselves of the Disability Inter-Group, in order to try to encourage the EU to promote and develop new policies and strategies, which can include our "Key Demands", particularly Personal Assistance services at a European level. We feel now is



the right time to encourage this debate at the European Parliament. This has been one of the goals of the year for ENIL.

We feel that it is unfair and unjust that some EU countries provide Personal Assistance services for their disabled citizens and others do not. It is only equitable and within the concept of harmonisation to make this available throughout the entire EU.

We hope that bringing the issues of these “Key Demands” to you today can open up a positive dialogue between us, to try and bring this change about. We therefore welcome the opportunity in seeking your expertise and knowledge of the EU institutions to help this process. We hope it will be possible to formulate a Resolution on our “8 Key Demands”, which can go to the European Parliament. May we end our presentation to you by thanking you for listening and look forward to trying to answer the questions you may have in order to explore the possibilities.

John Evans,

ENIL President, September 2003



Tenerife Declaration

Promote Independent Living and Discrimination against
Disabled People

We, four hundred participants from many European countries gathered at the 1st European Congress on Independent Living, held in Tenerife in the framework of the 2003 European Year for Disabled People, urge that the Canary Islands' and Spanish Governments take the lead in advocating for the implementation of this Declaration in European Union policy, specifically in the work for the upcoming Non Discrimination Directive on Disability, and the European Action Plan on Disability.

Principles of Independent Living

We, disabled people, must have the means to take responsibility for our lives and actions in common with non-disabled people. Most of the problems that disabled people encounter are not medical but social, economic and political.

After a history of marginalisation and exclusion, disabled people are NOW demanding the right to choose how we live our lives in the community. We demand the same opportunities and choices and the same degree of control and self-direction over our everyday lives that non disabled people take for granted.

Our full and equal participation in society will enable us to reach our maximum potential as human beings, and in so doing contribute to the economic and social life of the community. This has historically been denied us.

Disabled people must be viewed as the experts on their lives. As experts, we have the right and responsibility to speak on our own behalf. Furthermore, disabled people need to control our own organizations.

Independent Living is a fundamental Human Right for all disabled people regardless of the nature and extent of their impairment. These include people with learning difficulties, mental health system users and survivors, disabled children and older disabled people.

All life and diversity should be valued. Every human being should have the right to make choices about issues affecting their lives.



We Affirm

In all activities of the public sector such as infrastructure planning, education, transportation, employment measures and other services, the needs of disabled people must be fully taken into account through Universal and Inclusive Design. Service design and implementation must follow independent living principles and centre on a person's individual needs.

Personal Assistance enables persons with physical, sensory, intellectual, and other impairments to live a self directed life in the community, enabling fuller participation in

all human activities. Examples include, parenting, sexual activities, education, employment, environmental development, leisure, culture and politics.

Disabled people should have maximum control over disability and independent living related services. These should include public financing, advocacy, training, and peer support for people who may not be able, or wish, to take full control of their lives.

It is unacceptable that European disabled citizens are still kept in residential institutions, because of the lack of appropriate living alternatives in the community.

We stress that independent living support services are essential in order for disabled people to enjoy basic freedoms and must be funded by all Governments. We, disabled people from all over Europe, do not accept any funding limitations in regards to our basic freedom. If necessary we are ready to challenge these assumptions about the lack of resources.

European Union

We urge the European Union (EU) to continue to expand its human rights policies to improve the quality of life of disabled people through freedom of choice and higher quality of services.

We condemn any type of segregation and institutionalisation that are a direct violation of our Human Rights. Governments must implement and enforce legislation that protects the Human Rights and equal opportunities of disabled people.

We urge the EU to adopt measures that will guarantee and prioritise community based, over institution type, solutions in the area of disability support services.

Disabled people must be given the choice to convert disability related support services, that are currently received in kind, into the equivalent amount of direct payments.

In compliance with the Treaty of Rome, we demand that EU governments adopt a minimum level of direct payment for personal assistance services in all EU countries in order to promote freedom of movement within and between EU



states. Furthermore, in promoting standards for inter-operability of goods and services the needs of disabled people must be taken fully into consideration.

We demand that the EU require governments of European states fund the development and support of organisations controlled and run by disabled people to promote independent living.

We demand that the EU adopt the necessary measures to prevent discrimination against disabled people in future advances of genetics, science and technology.

Arona, Tenerife, April 26th, 2003



Conclusions of The Conference On Independent Living Of Disabled People

(Ljubljana, 22nd October 2003)

1. Information, mobility and accessibility of the environment and of all residential objects, and above all personal assistance, are key conditions for Independent Living of the disabled people

2. Personal assistance and mobility must become rights of an individual and are accomplished through direct payments. These assure necessary structural shift on the way to the realization of the basic human rights. In this way, equal opportunities for each individual are assured, and choosing as well as power to make decisions about one's life is made possible

3. Life in an institution generally prevents a disabled person from deciding about their own body and life; dignity and self-respect are taken away. That's why we are strongly striving for direct payments, a possibility to choose and deinstitutionalization. We suggest that funds destined for maintenance, renovation and building of institutions and for payment of officials are diverted into direct payments of services that a disabled person needs to reach independence (in living).

4. Accomplishment of the right for independent living of disabled people should not be limited by the excuse about »financial condition of the state«, because it is a realization of basic human rights which are universal and undoubted. As is the case in most of the countries, no extra funds are needed. The existing ones just need to be diverted or more effectively used.

5. Independent living must not become the matter of profession and professionals – it must remain in the hands of disabled individuals that live under the principles of independent living with the personal assistance and other services.



Conference On Independent Living Of Disabled People





Main duties and rights of the users included into the “Independent Living of disabled people” programme:

Rights:

1. To participate with the contractor in designing an Agreement on implementation of personal assistance and other activities inside the framework of “Independent Living of disabled people” programme.
2. To design a model of personal assistance (working hours, choice of assistant...) by oneself or with the help of the contractor...
3. To reject or dismiss an unsuitable assistant and get a suitable replacement
4. To request and receive all the information on the implementation of the programme
5. To take part in all public activities of the programme and be in the position to take part in decision making and designing the strategy of the development of the programme.

Duties:

1. To take part in the courses of education concerning the “Independent Living of disabled people” programme and implementation of personal assistance
2. To forward true information relevant for providing the services in the framework of the “Independent Living of disabled people” programme to the implementors of the project.
3. To consider the contractor’s requirements regarding administrative commitments:
 - a. forwarding the record of the assistant’s working hours to the coordinator of the project one month in advance and forwarding assistant’s record of attendance on the last day of the month for the current month (for salary invoice).



- b. To notify the contractors about the crucial circumstances that could affect implementation of work (disagreements with the assistants, absence from post set for implementing personal assistance...)
- c. To be included into the search of the assistant based on his/her abilities and circumstances.

Duties of the contractors of “Independent Living of disabled people” programme:



1. To take care of administrative, accountancy and substantive aspects of the programme and regular financial operation
 - a. payroll accounting, and payment of salaries,
 - b. to keep accounts and other records,
 - c. to write financial and substantive reports for the co-providers of funds
 - d. fulfilment of terms stated in the contract regarding programmes of subsidiary employment as well as the terms of the programme implementation contract.
2. To implement courses of education for the assistants.
3. To implement courses of education for the users.
4. To make provision and be responsible for expenditure of the means allocated.
5. To provide assistance with organizing the user's personal assistance (planning of working hours, help with keeping track of record of attendance...)
6. To advise the users and help them take care of the formalities or filling in various forms (regarding education, housing, disability status...)
7. To implement pre-selection and interviews with the candidates for the position of a personal assistant if necessary and to direct the suitable candidates to the users of the programme within range of possibility.



Centres for Independent Living

The local Centres for Independent Living are a form of agencies run by disabled persons and providing their clients with basic services for independent living – practical and legal advice, support in soliciting funds for employing personal assistants, counselling and providing of information, training of personal assistance candidates, mobile service... The tasks of coordinators in Centres include the keeping of employee records with information on their presence at work, mediation in possible conflicts between the employees and the clients and informing clients about other matters that concern them. The Centres for Independent Living should by no means be understood as buildings, communities or institutions, but as local or regional offices connected into national network. One of the important activities of the Centres is experience gathering and transmitting. Personal experiences and ways of overcoming difficulties may often be an encouragement or challenge to someone else, and a piece of advice can help one to avoid unnecessary waste of energy. The National Centre for Independent Living would be in charge of organizing and providing training for personal assistants, technical staff and those disabled persons who in opting for independent living desire to receive additional education.

For this vision to become a reality it would be necessary to set up a national fund for independent living to finance the costs of the Centres for Independent Living. Personal assistance financing should be regulated by law in the form of financial support of individuals and their needs. Such solution requires no new financial resources but only re – distribution of the existing resources that our State has “surrendered” to this field.



Elena Pečarič

What Independent Living is not?

It is certainly not a form of either educational or institutional care or a residential community. It is also not a life inside a family. Independent living is not about raising the quality of life; it is about basic human rights. What could one say it is? Primarily it is an opposition against medical discourse and apurtenant models of understanding physical and mental disability, homosexuality, people infected with the HIV virus..., which is one of the causes of discrimination. The right to create their own uniqueness; the right and duty to decide on all aspects of their life is often taken away from disabled individuals. The way of living is one of these basic choices. Independent living denotes a possibility to live as everybody else. It has to do with self-determination in the sense of letting other people know by ourselves of who we are and what we want; others should not speak in our name; doctors should not be saying that we are disabled and categorized into such and such a category and social workers should not be the ones saying what kind of care, custody, education and work in protected workshops we need. Independent living is the right to be autonomous in the sense of rejecting all options offered, which were prepared in good faith by others specifically for the disabled people and to take their own path. Independent living is a right and an option of insisting on the chosen path. It is a freedom of making wrong decisions and of learning from one's own mistakes. From what has been hitherto said, we can conclude that there is no one model; rather there is an infinite number of different models. That is why a single, generic model cannot be designed, predicted, controlled, directed or learned.

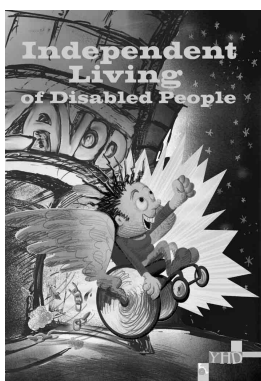
There is a risk, a leap into the unknown and uncertain. All the things the institutions take away from the individual, where his/her life is protected, secured and cared for by ways of routine practices and by methods and designs prepared in advance. Through miniscule habits and practices order, control and more often than not, terror is restored. To start an independent life, only a decision is needed and this decision can be made by anyone. However, of course, things are not as simple.



People whose legal capability to work has been taken away cannot make their own decisions. On the other hand, the physically disabled people are not much better off, as they are simply not given or offered a chance to speak for themselves. Their will is never in the centre of successive procedures and social welfare. Social workers actually do listen to their wishes occasionally, but repeatedly the same reasons crop up – at this moment their wishes cannot be realized as the law does not provide for them and the lack of resources render them impossible to fulfil. Therefore, such wishes remain just that – wishes. However, there are other possibilities, the social worker would say, and they are not that bad anyway. There will be others there, people like you, and in time you will get used to the environment and maybe even realize that you will have benefited from such an environment. You are not the only one and I have experience with your kind of people. Independence is always established in relation to someone or something and thus primarily depends on the type and the degree of handicap. For someone who is physically disabled, personal assistance is of vital importance, because this is the only way of satisfying the basic condition for a normal everyday life.

Abstract from the lecture at Faculty for Social Work

(Ljubljana, 18.5.2000)



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